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cleft xchange

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OFFICIAL CLAPAS FSG NEWSLETTER

CLAPAS FAMILY SUPPORT GROUP

Your effort and commitment to your children born with clefts is commendable. Lead them and give them a shoulder to cry on. Don't give up, though it's painful.

I'm a fellow cleft patient and I have written a poem to make your days brighter!

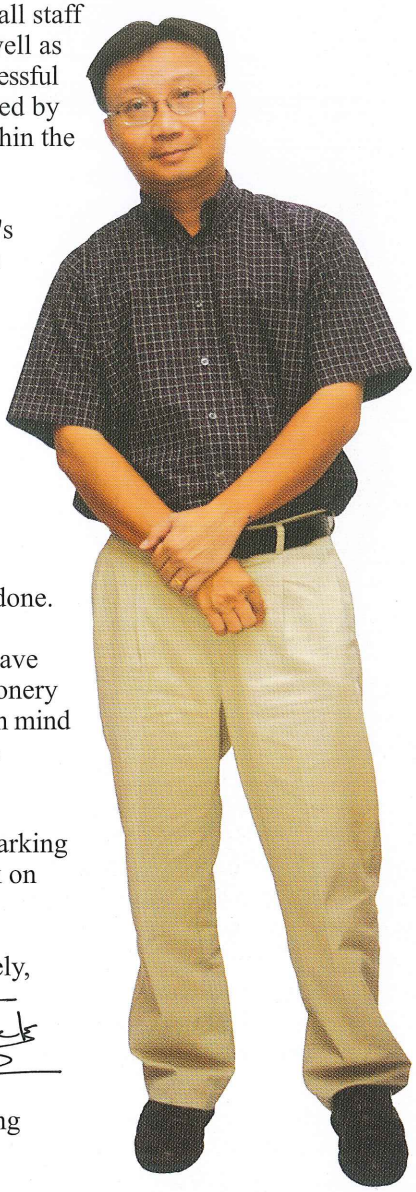
Seas run deep,
Needles cause pain.
Flowers bring beauty,
Sun brings light.
Children bring joy,
Choose love and live even
in times of diversity
When you love, you will give.
When you give, love goes within.
Sincerity can only be seen
through the eye of the heart.

Love,
Bridget

chairman's message

Dear FSG members,

I was delighted to personally meet many of you at the last FSG Talk in August 2004. I would like to thank all staff and volunteers of the NKF, SGH and KKH, as well as the families who came, for making the event a successful and memorable one. I was particularly encouraged by the large turnout, which shows that the spirit within the FSG is still strong after all these years.



Through our partnership with the NKF Children's Medical Fund (CMF) in May 2004, the FSG has achieved the following:

- Formed a FSG committee
- Organised a talk by Dr Vincent Yeow in August 2004
- Visited about 15 families and rendered financial assistance for cleft treatment
- Created a FSG member database

In spite of the above, much more remains to be done. In the midst of the festive seasons, the FSG is mindful that there will be families, who will have difficulties in purchasing school textbooks, stationery and shoes for the new school term. It is with this in mind that the committee has disbursed financial aid to 10 families.

The next project that the committee will be embarking upon will be the creation of a web site and a talk on 19 March 2005.

Yours sincerely,

Richard Cheng

contents

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CHILDREN'S MEDICAL FUND

overview of orthodontic management of cleft

Cleft lip and cleft palate is the fourth most common birth defect in the United States. One in every 700 newborns is affected by cleft lip and/or cleft palate. In Singapore, one in every 650 newborns is affected by this condition.

A cleft lip is a separation of the two sides of the lip. A cleft palate is a separation of the bones of the upper jaw and/or upper gum, causing an opening in the roof of the mouth. The cleft lip and/or palate occur during development of the foetus when the two sides of the lip and/or palate do not fuse or join together.

What is Orthodontics?
Orthodontics is a branch of dentistry that specialises in the diagnosis, prevention and treatment of dental and facial irregularities.

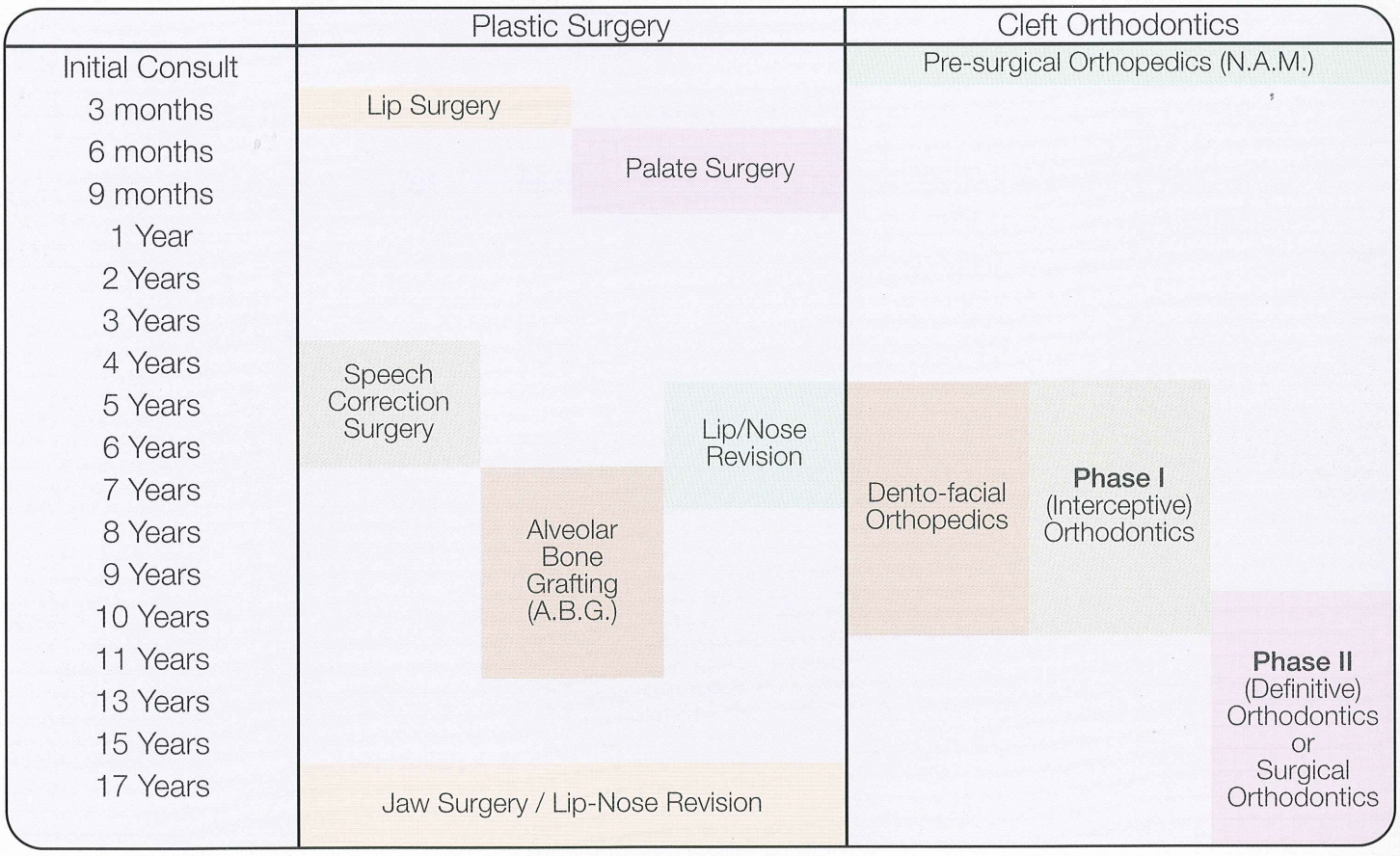
Why is Orthodontics important?
A cleft of the lip, gum (alveolus), and/or palate in the front of the mouth can produce a variety of dental problems. These may involve the number, size, shape, and position of both the baby teeth and the permanent teeth. There is also a higher tendency for cleft children to develop jaw growth problems.

An orthodontist is a specialist who straightens the teeth with braces and aligns the jaws to re-establish the facial balance by modifying jaw growth pattern orthopedically (non-surgically) and repositioning the jaw (surgically).The surgical procedures are carried out with the help of a cleft surgeon.

When should my child's orthodontic treatment begin?
Orthodontic Cleft Care is generally divided into the following stages for optimal care/results:

0-3 months – Pre-surgical Orthopedics and Naso-alveolar Moulding (N.A.M.)
5-10 years – Dento-facial Orthopedics
7-12 years – Alveolar Bone Grafting (A.B.G.) & Interceptive Orthodontics (Phase I)
10-12 years – Comprehensive Orthodontics (Phase II)
16 years & above – Surgical Orthodontics (Orthognathic/Jaw Surgery)
(Refer to Table 1 for treatment timetable)

Table 1 Cleft Lip and Palate Treatment Timetable



What would happen if my child was left untreated?

Many cleft-orthodontic problems become worse, more difficult and more costly to treat, if they were left untreated for many years. The final treatment result is often less desirable, when compared to those children who are managed by a cleft team over their growing years.

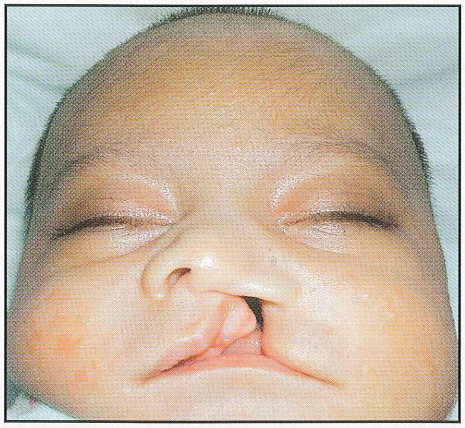
The following are the most common problems:

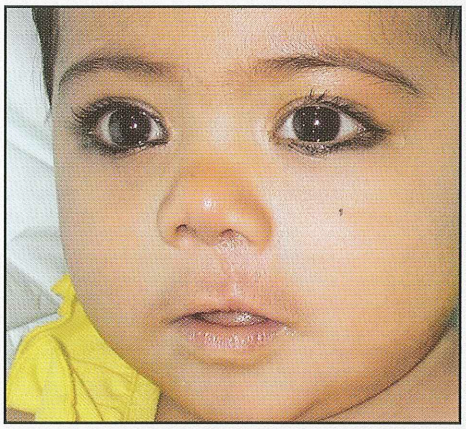
- Food/water coming through the nose
- Presence of hole/ holes ('fistula') in the palate
- Unclear speech
- Teeth coming into the mouth at unusual places
- Collapsed jaws
- Asymmetric face (or crooked face)
- Underdeveloped mid-face (The 'long-chin' & 'thick lower lip' look)
- Premature loss of teeth
- Missing teeth or too many teeth
- General lack of self-esteem (confidence)

Is it important for my child to be treated by an orthodontist who is a member of a cleft/multidisciplinary team?

Children born with clefts or other craniofacial conditions often face multiple, complex health problems. A child born with a cleft frequently requires several different types of services, e.g., surgery, dental/orthodontic care, and speech therapy, all of which need to be provided in a coordinated manner over a period of years. This coordinated care is provided by interdisciplinary cleft palate teams comprised of professionals from a variety of health care disciplines who work together on the child's total rehabilitation. Experience has shown that an interdisciplinary team of specialists who work together to manage these complex issues produces the best results.

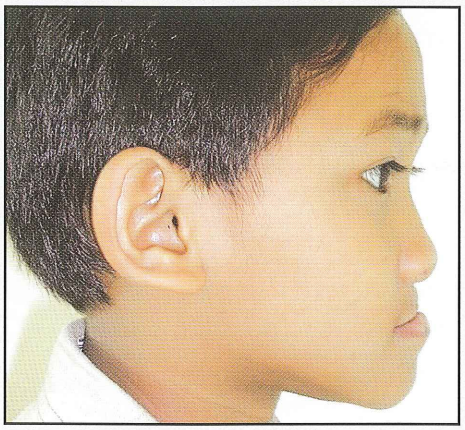
The goal of the cleft team is to ensure that care is provided in a coordinated and consistent manner, with the proper sequencing of evaluations and treatments within the framework of the patient's overall developmental, medical, and psychological needs. Since growth is a significant factor in determining the ultimate outcome of treatment, the child must be assessed thoroughly and regularly by the team until young adulthood.

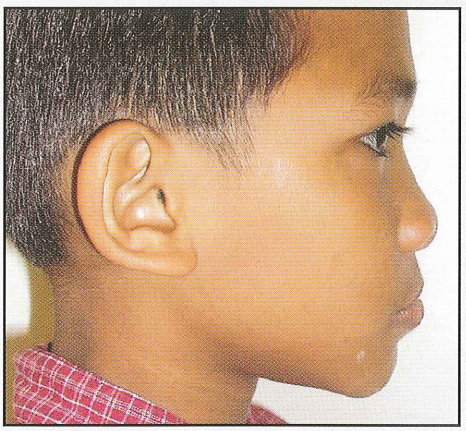




BEFORE (left) – A child born with a right unilateral cleft lip and palate

AFTER (right) – Child treated with Naso-Alveolar Moulding (N.A.M.) and 3-in-1 combined surgery





BEFORE (left) – An 8-year-old cleft patient with Mid-face Deficiency – this is seen as the "big lip" or "long-chin" look

AFTER (right) – Mid-face correction after 6 months of Dento-facial Orthopedics (without surgery)

(This is an introduction to a series of four Cleft Orthodontics management articles.)

Special thanks to Dr Catherine Lee (Camden Medical Centre), Consultant, Cleft and Craniofacial Centre, KK Women's and Children's Hospital, for contributing this article.

reflections (english version)

Hi, my name is Hairuna and I am 26 years old. I have been given the task of writing a little about myself in this newsletter. I am the eldest child in the family and I was born with a bilateral cleft lip and palate. My birth was premature and I was very underweight.

During that time, cleft lip and palate was not a common thing and it became very stressful for my mum who was only 17 years old when she had me. Because of the absence of a support group at that time, my parents were at their wits' end. They did not know whom they should meet and share their opinions with. All they could do was to follow the doctor's instructions.

My parents were then introduced to Professor ST Lee, at the Singapore General Hospital. His advice to my parents at that time was, I should be given time to put on a little bit of weight and when I am all chubby and healthy, I would undergo cleft lip repair.

From one surgery, I began my journey as a cleft lip patient. My days as a child were always laced with visits to Professor ST Lee's clinic, the speech therapist and my orthodontist. Every time I had an appointment with all these specialists, my parents would accompany me. They made sure I was happy and eager to meet all of them. They treated those days like family days, and as a child, I always looked forward to them. My school days were, of course, very thorny as my peers could not understand why my speech was different from theirs. They also kept asking why there were scars on my lip and why my nose was not like theirs. I am fortunate to have parents who have taught me to be a patient person and am prepared enough to answer their questions.

Maybe this is the way God has arranged my life. By making me a cleft lip patient, I am brave enough to face challenges, am always on the lookout to prove to people that even though I may be lacking in the looks department, that does not mean that I lack moral values and emotions. I am easily touched when I see people who are less fortunate than I am and I think ahead for my age.

Now, after all my surgeries, I do not look like a cleft patient. The amazing thing is that some people do not know that I am a cleft patient if I do not tell them. When I walk with my two younger sisters, I do not look any different from them. Well, I have to thank a lot of people for this, especially Professor ST Lee, Dr Vincent Yeow, the nurses at the Singapore General Hospital, speech therapists, my orthodontists and of course, my parents, without whose support and motivation, I could have been very lazy and not bothered to attend all the clinics that were arranged for me by the specialists.

If I look at the situation now, I am really grateful and happy because there is already a Family Support Group. When my mother gave birth to me, there was no one she could talk to. But with the existence of a strong Family Support Group, parents of cleft lip children now have a place to share their concerns and get to know other parents of cleft children and help each other. I am certain that with this Family Support group and with members who are always willing to help, parents of cleft lip children will not feel lonely and confused.

Last but not least, children are children. Whether they are born with a cleft or born normal, they are still God's gift to us. We might ask ourselves, why are we chosen to have cleft lip children? But who knows if these cleft children might be the light in our lives when they grow up? Support your children, give them the same amount of love as you would give to your other children, and do not differentiate between them. God willing, they will be the ones who will always make us smile and be joyous.

Till next time, bye!

Hairuna Bee Bte Safiqur Rahman
Research Assistant
Dept of Plastic Surgery
Singapore General Hospital

reflections (malay version)

Salam sejahtera. Nama saya Hairuna, berusia 26 tahun. Kali ini, saya diberi tugas untuk menceritakan sedikit tentang diri saya untuk newsletter ini. Saya anak sulung ibu dan ayah saya, dan dilahirkan dengan sumbing bibir dan langit-langit (Bilateral Cleft Lip and Palate). Saya dilahirkan tidak cukup bulan dan berat badan saya terlalu ringan.

Pada waktu itu, tidak ramai yang tahu apakah itu sumbing bibir dan menjadi satu tekanan buat ibu saya yang berusia hanya 17 tahun ketika melahirkan saya. Kerana tidak ada kumpulan sokongan pada waktu itu, ibu dan ayah saya sebagai kebingungan. Mereka tidak tahu pada siapa yang harus mereka bertemu dan berkongsi pendapat. Mereka hanya dapat mengikut nasihat doktor.

Ibu dan ayah saya pun diperkenalkan kepada Professor ST Lee, di Singapore General Hospital. Nasihatnya pada masa itu, saya harus diberi masa untuk menambah berat badan dan jika saya sudah cukup sihat, pembedahan akan dilakukan untuk mencantumkan semula bibir saya yang sumbing.

Dan dari satu pembedahan, bermulalah perjalanan saya sebagai seorang pesakit sumbing. Hidup saya sewaktu kecil diiringi dengan kunjungan ke klinik Professor ST Lee, speech therapist dan doktor gigi. Setiap kali, saya mempunyai temujanji dengan pakar-pakar ini, saya akan pergi ditemani ibu dan ayah saya. Ibu dan ayah saya memastikan saya gembira bertemu dengan pakar-pakar ini. Ibu dan ayah saya akan menjadikan hari temujanji itu sebagai hari riadah keluarga, jadi saya sebagai seorang kanak-kanak sentiasa akan menunggu-nunggu hari itu.

Zaman sekolah saya memang dipenuhi ranjau kerana rakan-rakan sebaya saya tidak akan faham mengapa cara percakapan saya lain dengan mereka. Mereka juga akan kerap bertanya mengapa saya mempunyai parut diatas bibir, mengapa hidung saya tidak seperti hidung mereka. Saya bertuah kerana mempunyai ibu bapa yang telah mendidik saya menjadi orang yang penyabar dan pandai menjawab soalan mereka semua.

Mungkin inilah cara Tuhan mengatur hidup saya. Dengan menjadikan saya seorang pesakit sumbing, saya lebih berani menghadapi cabaran, ingin selalu membuktikan kepada orang yang jika saya kekurangan dari segi rupa, tidak semestinya saya kekurangan dari segi akhlak dan emosi. Saya senang terusik perasaan jika terlihat orang yang lebih tidak berdaya dari diri saya. Saya juga berfikiran lebih dewasa dari usia saya.

Sekarang setelah semua pembedahan saya, saya tidak kelihatan seperti seorang yang dilahirkan sumbing. Ada yang tidak tahu yang saya ini sumbing jika saya tidak memberitahu mereka. Jika saya berjalan bersama dua adik perempuan saya, saya tidak akan dilihat seperti lain dari mereka. Semua ini adalah hasil usaha-sama Professor ST Lee, Dr Vincent Yeow, jururawat-jururawat di Singapore General Hospital, speech therapists dan semua doktor gigi saya. Dan paling penting ialah ibu bapa saya, kerana tanpa sokongan kuat dan dorongan mereka, mungkin saya akan leka dan lalai untuk menghadiri segala klinik-klinik yang diaturkan oleh pakar-pakar tersebut.

Jika dipantau keadaan sekarang, saya sangat bersyukur dan gembira, kerana sudah ada kumpulan sokongan (Family Support Group). Kerana sewaktu ibu saya memerlukan teman bicara sewaktu saya dilahirkan, dia tiada tempat mengadu. Tetapi dengan adanya Family Support Group, anda sebagai ibu bapa kepada kanak-kanak sumbing, sudah ada tempat meluahkan perasaan. Sudah ada tempat untuk berkenalan dengan ibu bapa kanak-kanak sumbing yang lain. Sudah boleh menolong antara satu sama lain.

Saya berharap dan pasti dengan adanya Family Support Group, dan juga dengan adanya ahli-ahli yang akan sentiasa menghulurkan tangan untuk membantu, anda sebagai ibu bapa kanak-kanak sumbing tidak akan merasa kekosongan atau kebingungan.

Akhir kata, kanak-kanak adalah kanak-kanak. Sama ada mereka dilahirkan sumbing atau normal, mereka tetap anugerah dari Tuhan untuk kita. Mungkin kita akan bertanya mengapa kita yang dipilih mempunyai anak yang sumbing? Tetapi, siapa yang akan tahu, jika anak yang sumbing inilah yang akan menjadi pelita hidup kita ketika dia dewasa nanti. Sokongilah anak anda, berilah mereka kasih sayang yang sama seperti adik-beradik mereka, jangan beza-bezakan mereka, Insya'Allah, merekalah yang sentiasa membuat kita mengukirkan senyuman dan merekalah yang akan sentiasa menggembirakan kita.

Sehingga dilain kesempatan, sekian.

Hairuna Bee Bte Safiqur Rahman
Research Assistant
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Singapore General Hospital

preparing your child for social situations

The goal for all parents is to nurture their children so that they have a positive sense of self, and ultimately make a contribution to their community. To achieve this goal, parents need to build self-esteem and confidence in their children. We know that children with facial differences may require additional skills to deal with the special situations that they face. This fact sheet provides basic advice on cultivating these skills.

Identifying the Condition

As your child grows, it will be important for him or her to understand the facial condition and be able to share information about it with others, particularly when you are not there. Preparing for social interaction begins at a very early age through your example as a parent. Your child will learn how to answer questions about his or her condition by watching the ways in which you respond to people. It is important for you to think about the message you want to give to your child. There will be days when you feel able to educate others through a simple explanation of your child's condition, and there will be days when you are less patient or do not have the emotional strength to deal with others' questions. It is important to have responses prepared for both situations.

When preparing responses, find words to describe your child's condition that are truthful and appropriate to your child's age. Remember that your child will be listening to what you say. For example, a simple statement that a cleft lip scar is from a "hole in my child's lip when he was born" may be sufficient when your child is young. As school age approaches, your child can and should learn the proper terms associated with his or her condition. This knowledge provides your child with self-confidence based on an ability to respond to and educate others. It is important that your child has a positive statement to give to avoid feeling awkward, embarrassed, or uncomfortable. Being prepared to answer questions removes the element of surprise and makes social experiences easier.

Knowledge of Personal History

Children need to have a sense of their personal history. Making photographs available to your child as part of the family photo album is a critical part of helping your child accept his or her history as "normal". Children love to look at their baby pictures; these photos will document the changes in your child's appearance that have occurred with growth. Allowing your child access to the family album will provide opportunities for discussion in a non-threatening atmosphere, in which your child can ask questions about his or her condition. By including all your child's photos, you can show your child that you are proud of who he or she is.

Handling Negative Social Interactions

All children are teased for something at some time in their lives. The only difference is what they are teased about! Parents often become angry with children who tease and may want to confront their parents. Before taking action, however, it is a good idea to ask your child how he or she wants to handle the situation. Allow your child to express his or her feelings to you. Questions to consider with your child include the following: Who did the teasing? Was it a friend, an acquaintance, a stranger, or a school bully? What was your child teased about? Was it a mean comment, a joke that went bad, or a remark based on a lack of understanding?

Making photographs available to your child as part of the family photo album is a critical part of helping your child accept himself or herself.

After looking at these factors, you and your child can decide how to respond in future encounters. Some choices include making a good-natured joke, providing information, or turning away from the person doing the teasing and actively engaging in positive interaction with other peers or friends. Whatever the response, your child should do it with confidence reflected in body language and tone of voice. Parents can practice these strategies with their child. However, if teasing continues to be a concern, it may be helpful to involve the other children's parents, a teacher, or a health care professional. Seek guidance from the professionals on your child's craniofacial team, who will be able to provide information specific to your child's situation.

Networking with Others

Many families have found that talking with others, who are dealing with similar situations, is a very empowering and educational experience. Your child's team coordinator or other support organisations may be able to refer you to other resources or help you identify other families who would be interested in talking with you.

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